UCL
GREAT ORMOND STREET INSTITUTE OF CHILD HEALTH

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THE NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY CHARITABLE TRUST

Paediatric Epilepsy Research and Impact Report

2025

Young Epilepsy

Contents

Introduction

I am delighted to present our annual research report for the period July 2024 to June 2025 for the paediatric epilepsy research unit across Young Epilepsy, UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children.

2025 has been an exceptional year for our research programme, distinguished by fantastic progress and the achievement of several key milestones. Over the past twelve months, we have conducted 48 active projects, initiated 6 new studies and brought 5 to completion. Among the highlights are the development of a gene therapy for deoxyguanosine kinase deficiency, a devastating mitochondrial disorder of infancy, and the creation of digital models of brain function to enhance localisation of focal epilepsies and predict individual treatment responses. We are also advancing a novel MRI technique and exploring a potentially transformative treatment designed to reset dysfunctional brain circuits through a single, minimally invasive procedure.

Our commitment to improving outcomes for children and young people with epilepsy is further reflected in projects such as the development of international consensus guidelines for diagnosing and managing Pyruvate Dehydrogenase Complex Deficiency, and a comprehensive scoping review on the transition from paediatric to adult healthcare. These diverse initiatives evidence our commitment to advancing knowledge and making a tangible difference across all aspects of childhood epilepsy.

The impact of our research is evident in this year's publication record. Between July 2024 and June 2025, we produced 96 peer-reviewed research articles and 26 reviews and expert commentaries. Notably, five of these publications ranked among the top 5% of all research worldwide, highlighting their global significance and quality. Standout publications include a study utilising graph neural networks to detect epileptogenic focal cortical dysplasia from MRI data and a position paper presenting the updated International League Against Epilepsy classification of epileptic seizures.

A particular highlight of the year was the 15th Paediatric Epilepsy Research Retreat in January 2025, moderated by Professor Nicola Specchio, Chair of Neurology, Epilepsy and Movement Disorders Unit at Bambino Gesù Children's Hospital, and Director of the Research Unit on Neurological and Neurosurgical Diseases in Rome, Italy. The retreat continues to bring together early-career and established researchers, fostering collaboration and the exchange of ideas within a multidisciplinary forum.

Young Epilepsy's vision is to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected, and their ambitions realised. Our collaborative research programme exists to establish successively better outcomes by driving early diagnosis and intervention in every aspect of childhood epilepsy. I do hope you enjoy reading this report and feel inspired by the progress made in improving the lives of children and young people with epilepsy.

Professor Helen Cross OBE
The Prince of Wales's Chair of Childhood Epilepsy

Who we are...

Led by the Prince of Wales's Chair of Childhood Epilepsy, Professor Helen Cross, our research programme is a collaborative scheme between Young Epilepsy, Great Ormond Street Hospital and UCL GOS - Institute of Child Health.

Collaboration and integrated working across the partner organisations puts us in a unique position to incorporate data which spans:

- The entire range of complexity and comorbidity in epilepsy.
- All stages of diagnosis and care.
- The full age range, from neonates to young adults.
- Multidisciplinary expertise to improve holistic understanding of epilepsy and service design.

The Prince of Wales' Chair of Childhood Epilepsy is jointly grant funded by GOSH charity and Young Epilepsy

Young Epilepsy exists to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

Childhood epilepsy can be frightening, isolating and often a misunderstood condition. We work with children and young people with epilepsy, to ensure their voices are heard. Young Epilepsy:

- Campaigns for the rights of children and young people with epilepsy
- Delivers health services and research that improve epilepsy diagnosis and epilepsy treatments
- Supports children and young people with epilepsy throughout school, college, and university
- Provides information, guidance, and practical help for living everyday life with epilepsy

Great Ormond Street Hospital for Children (GOSH) is an international centre of excellence in child healthcare, at the forefront of paediatric training in the UK. Together with UCL GOS - Institute of Child Health, GOSH forms the UK's only Biomedical Research Centre specialising in paediatrics. Most of the children we care for are referred from other hospitals throughout the UK and overseas. There are 63 different clinical specialties at GOSH; the UK's widest range of specialist health services for children on one site. 60% of the UK's epilepsy surgeries are carried out at GOSH.

University College London Great Ormond Street-Institute of Child Health (ICH) together with its clinical partner Great Ormond Street Hospital for Children (GOSH), forms the largest concentration of children's health research in Europe.

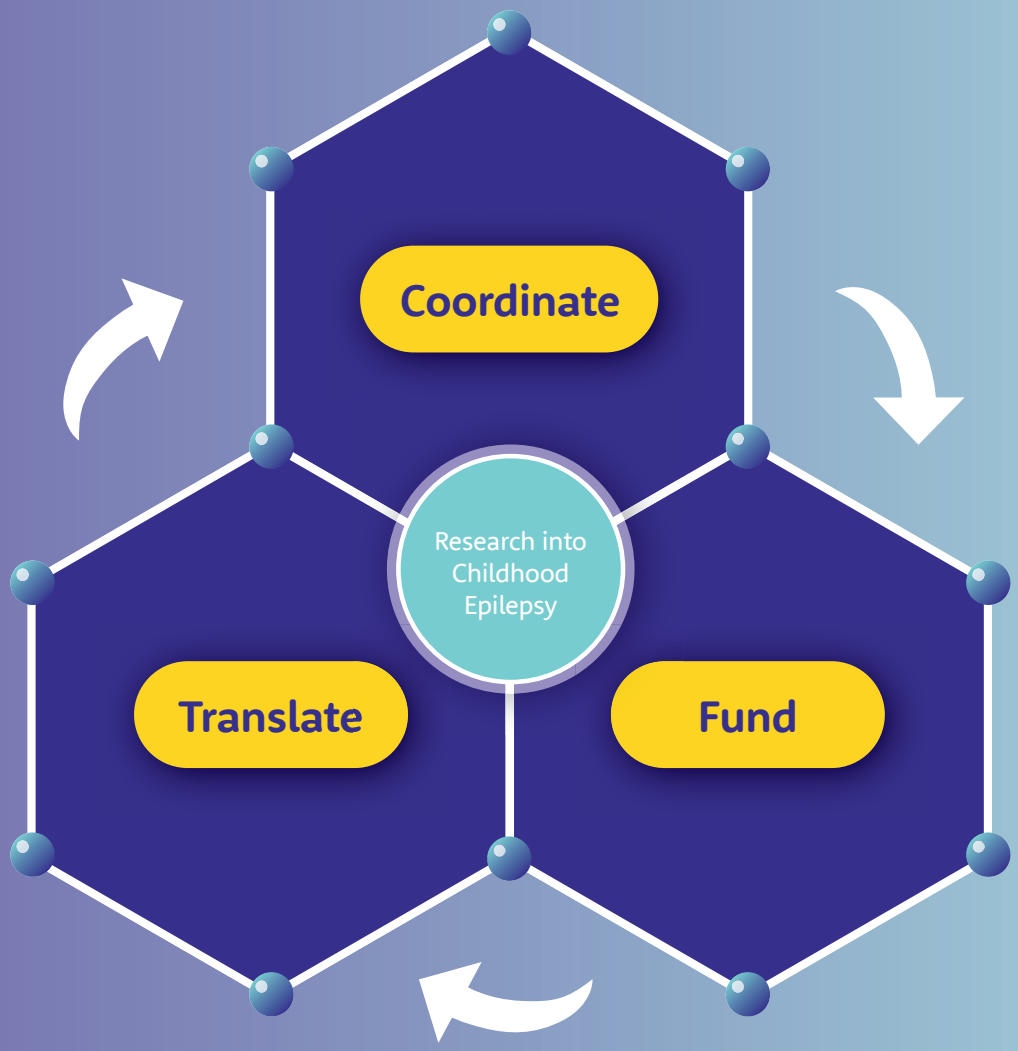
The inspirational mission of the UCL Great Ormond Street Institute of Child Health is to "improve the health and well-being of children, and the adults they will become, through world-class research, education and public engagement".

The academic strategy of GOS ICH is focused on five scientific research and teaching departments:

- Developmental Neurosciences
- Developmental Biology and Cancer
- Genetics and Genomic Medicine
- Infection, Inflammation and Immunology
- Population Policy and Practice

What We Do...

Our research programme exists to ensure the best outcome for every child by optimising diagnosis, treatment, and support for all aspects of childhood epilepsy



Animal Welfare Policy

The welfare of animals used in research is very important to Young Epilepsy, GOSH and ICH. Researchers would prefer not to use animals at all so we follow the guidance of the Association of Medical Research Charities. These principles are called the 3Rs:

- **Replace** the use of animals with alternative techniques or avoid the use of animals altogether.
- **Refine** the way experiments are carried out, to make sure animals suffer as little as possible. This includes better housing and improvements to procedures which minimise pain and suffering and/or improve animal welfare.
- **Reduce** the number of animals used to a minimum by seeking ways to find out information from fewer animals or more information from the same number of animals.

Research Strategy & Goals

Workstream 1: Understanding Childhood Epilepsies

Around half of people diagnosed with epilepsy never learn the cause of it. This is concerning from both the personal and clinician perspective. The more we know about what causes epilepsy and how else the underlying cause is affecting the individual patient, the better clinicians can manage and treat, and the better the patient can understand themselves.

GOAL 01

Gain a better understanding of the medical causes of epilepsy

26% projects currently contribute to this goal

The majority of epilepsy treatment is symptomatic. The more we know about the underlying causes of the epilepsies, the more chance there is of developing curative, targeted treatments. Under this goal we run:

- Cohort studies to evaluate prevalence, natural history and outcome of comorbidities
- Studies to determine the molecular or genetic basis to the epilepsies
- Collaborative outcome studies
- Enhanced structural studies using neuroimaging to increase detection of structural correlates
- Pathological examination of tissue from surgical specimens to enhance our understanding of structural correlates and related epileptogenesis

GOAL 02

Gain a better understanding of how epilepsy affects development and behaviour

26% projects currently contribute to this goal

Epilepsy is associated with myriad comorbidities. Evidence suggests that the effects of these comorbidities have a greater impact than seizures over the course of someone's life. This work will help us to understand how to treat epilepsy holistically. Under this goal we run:

- Cohort epidemiological studies to determine incidence, prevalence and outcome
- Population and family studies to gain further insights into new treatments
- Correlative studies in neurophysiology to enhance detection of origin
- Experimental animal model studies* to examine the effects of epileptiform discharges on development
- Correlative neurophysiology and neuropsychology studies

Workstream 2: Outstanding Treatment

Epilepsy treatments have not changed very much over time and the process of finding the right combination of treatments for each patient takes a long time. This is very hard on patients – especially if they are young. Continued advancement of imaging, surgery, dietetics, genomics and targeted treatment, and new medicines is crucial in the quest to effectively treat, and one day perhaps cure, every epilepsy.

GOAL 03

Improving diagnosis and treatment to determine the benefits of early interventions in improving long-term outcomes

31% projects currently contribute to this goal

The longer one has epilepsy, the longer its underlying cause is able to threaten or cause damage. Effective diagnostic processes, optimal treatments and early intervention are vital in slowing or halting any damage. Under this goal we run:

- Short and long-term evaluation of outcome following early epilepsy surgery
- Evaluation of new medical treatments
- Evaluation of educational intervention
- Novel diagnostic and imaging methods

Research Strategy & Goals

Workstream 3: Outstanding Support

This workstream is set to tackle the wider challenges associated with growing up with epilepsy and in treating childhood epilepsies. It is important to know what epilepsy is and how to treat it but if the systems and supports are not in place to act on this knowledge then patients cannot benefit.

GOAL 04

Gain a better understanding of barriers to learning and determine the benefits of educational interventions

***5%** projects currently contribute to this goal*

We know that epilepsy can affect the way people learn and therefore may significantly affect someone's academic achievement if not properly understood. We want to know exactly what the challenges are and how best to support children with epilepsy in education. Under this goal we run:

- Evaluation of measures of progress in children with severe impairments
- Evaluation and development of targeted educational interventions across all educational settings
- Evaluating and enhancing the understanding of professionals working with children with epilepsy

GOAL 05

Make life better for children and families and make support systems more effective

***20%** projects currently contribute to this goal*

Childhood epilepsy can affect the whole family and treatment must involve multiple disciplines and agencies. Support for families must be evidenced and treatment pathways made more efficient with family voice always reflected in research. Evidencing these needs allows service providers to plan more effective services. Under this goal we run:

- Patient and public inclusion and representation in research design and management
- Interventional behaviour programmes
- Rehabilitation and follow-up studies
- Assessment of service provision
- Evaluation of the impact of epilepsy on family life
- Evaluation of the economic costs involved in epilepsy care

GOAL 06

Develop a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners

***2%** projects currently contribute to this goal*

To ensure the continuation of excellent research in paediatric epilepsy by nurturing future talent and continually improving knowledge. Under this goal we run:

- Development of training fellowships
- Projects working towards higher degrees with encouragement for independent working thereafter
- Joint working between ICH, GOSH and Young Epilepsy
- Enhancing research and interoperability across all areas of expertise
- Providing specialist education events and networking opportunities

Research Projects

Young Epilepsy

This section provides a brief overview of two key projects from this year's work. This is followed by a summary list of the current and competed projects during July 2024 to June 2025.

The projects are presented under the workstream that they contribute to most.

To find out more details about each of these projects please visit:

www.youngepilepsy.org.uk/what-we-do/health-research/research

Key Projects

Turning6: A Clinical and Neurodevelopmental follow up of EPIPEG participants

Investigators:

Colin Reilly, Abigail Wooldridge, Lara Carr, Joe Paternoster, Manuela Pisch, Finbar O'Callaghan, Helen Cross.

Background:

Epilepsy in the first year of life is associated with difficult to treat epilepsy and poor neurodevelopmental outcomes, severely affecting child and parent/caregiver quality of life and the child's educational outcomes. Despite this, there is a paucity of longitudinal data on children with early onset epilepsy with respect to neurodevelopment course and outcomes. This makes it difficult to understand the role of seizures, aetiology and treatment. Such data is vital to understanding prognosis in children with early onset epilepsy. Understanding factors associated with impairments will help direct prognosis but also management. The Epilepsy in infancy: relating phenotype to genotype (EpiPEG) study recruited 115 infants who developed epilepsy in the first year of life. The children were reviewed clinically, where appropriate underwent genetic testing and completed a full neurodevelopmental assessment including measures of global development, sleep, and parent/caregiver wellbeing. We are following up this unique cohort of children as they reach 6-10 years and undertaking comprehensive psychological assessments with the child, their parent/caregivers and teachers. This will allow us to characterise the neurodevelopmental (cognition, autism and ADHD status, sleep, health related quality of life) status of children who had epilepsy but also examine the association between initial neurodevelopmental and clinical assessments, and performance at follow-up.

Project Aims:

- Characterise the neurodevelopmental (cognition, behaviour, sleep) status of children who had epilepsy in the first year of life
- Examine the association between initial neurodevelopmental and clinical assessment results and performance at follow-up
- Examine factors, including epilepsy factors and neurodevelopmental status, assoicated with current performance and changes in performance between initial assessment and follow-up

Methods:

All eligible EPIPEG participants (n=109) have been contacted by telephone, email or in writing to participate in Turning6. Once consent is received, parents complete the Vineland Adaptive Behaviour Scale 3rd edition:

caregiver interview, with the study team via MS Teams. We complete a cognitive assessment with the child, using the Wechsler Intelligence Scale for Children, fifth edition (WISC-V) or the Bayley Scales of Infant and Toddler Development, third edition (Bayley-III), depending on the child's level of cognitive ability based upon Vineland-III performance.

We are also collecting information on the children's neurodevelopmental diagnoses, schooling, sleep and emotions/behaviour via a questionnaire booklet given to parents and teachers including measures such as Strengths and Difficulties Questionnaire (SDQ) and the Quality of Life in Childhood Epilepsy questionnaire (QOLCE).

We are also recruiting a control group of children (n=60-80) matched on age and gender with the children initially assessed in EpiPEG. Children in both groups will wear a Phillips Respironics Actiwatch2 for ten days, which measures several sleep variables such as sleep duration, fragmentation, and efficiency. Caregivers and parents of children also complete complementary measures of sleep (sleep diaries, survey) and behaviour. This will allow us to compare sleep in children with early onset epilepsy to age and gender matched controls.

Preliminary Findings:

To date, we have recruited 51/109 eligible EPIPEG families, and 15 have declined participation. Preliminary findings suggest that children with 'active' epilepsy have a significantly lower level of adaptive behaviour compared to those without 'active' epilepsy. The EPIPEG children also had significantly more behavioural problems on the SDQ than controls.

What this means:

Children with epilepsy onset in infancy have a significant neurobehavioral burden at follow-up, reflected in a high level of intellectual disability and worse behaviour than peers. Children with 'active' epilepsy at school age have worse adaptive behaviour and require more support in school than children who no longer have 'active' epilepsy.

Our follow-up of this unique cohort will significantly enhance understanding of neurodevelopmental course in children with early onset epilepsy. Additionally, understanding factors associated with impairments will help direct prognosis and management. We anticipate that data collection will continue until March 2026.

Gene-STEPS:

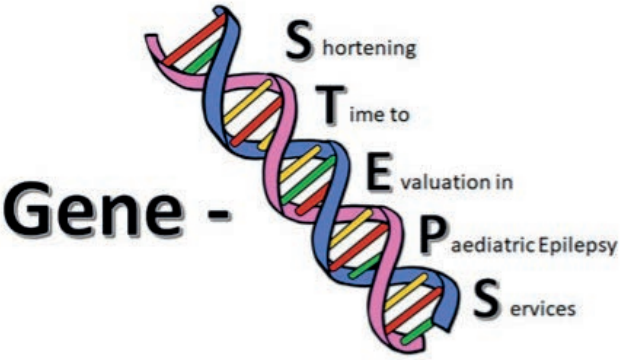
Shortening the Time of Evaluation in Paediatric epilepsy Services

Investigators:

Amy McTague, Helen Cross, Lyn Chitty, Neil Sebire

Co-Investigators:

Annapurna Poduri (Boston Childrens), Katherine Howell, Ingrid Scheffer (Royal Childrens Hospital Melbourne), Gregory Costain, Vann Chau (The Hospital for Sick Children Toronto)



Background:

This is the first project of the IPCHiP (International Precision Child Health Partnership) consortium. This consortium has been established by four of the world's leaders in child health research and care - Boston Children's Hospital (US), Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health (UK), Royal Children's Hospital Melbourne and Murdoch Children's Research Institute (Australia), and The Hospital for Sick Children ("Sick Kids", Canada). Together, they are sharing expertise, knowledge, and data to tackle and solve major child health challenges. The focus is rare diseases. Individually these diseases are uncommon, but collectively they affect up to six per cent of the global population - about 300 million people. For families, getting to the point of diagnosis is costly in time, money, stress, and emotion.

With whole genome sequencing and other technologies, we can transform how we diagnose and treat these devastating diseases. For too many children though, these approaches remain out of reach because they're not yet standard of care or funded by government. Gene-STEPS is a study of the impact of rapid genomics to diagnose severe forms of epilepsy in babies. This three-year study has the potential to transform lives for babies with epilepsy - and to establish a model that can be used to rapidly diagnose and treat other diseases in childhood.

In the past decade, the genomic revolution has led to the identification of underlying genetic aetiologies for childhood epilepsy, in the form of monogenic disorders affecting ion channels, neurotransmitter receptors, synaptic proteins, and other families of proteins. In a growing number of cases, the specific genetic diagnosis informs prognosis and genetic counselling, leads to the opportunity to participate in natural history studies, and even to changes in treatment that, to date anecdotally, may change outcomes in seizures and in neurodevelopment. However, a major challenge in clinical practice is that early intervention requires early diagnosis.

Currently the diagnostic odyssey in early-onset epilepsy is long and arduous for patients and their families. The timing and nature of genetic testing for such patients varies widely within and across countries and institutions. Our collective expertise includes epilepsy genetics research, genomic research, clinical epilepsy, clinical trials, and team science across the four leading paediatric institutions in the IPCHiP Consortium. Each of our institutions has a proven track record of discovery and translation to patients, and our combined efforts in epilepsy will set a new standard for multi-institutional research, data sharing, and improvement

To investigate our hypothesis that rapid genetic diagnosis and tailored management could improve outcomes, we proposed a novel approach to streamline and accelerate diagnostics in these severely affected children. We planned to evaluate children at diagnosis of epilepsy and institute rapid genome sequencing (result within 21 days). Our objective was to direct more appropriate treatments; outcomes would then be evaluated after 12m and 2.5 years

To date, 118 children and families have been recruited, with an additional 58 in the extension study, bringing us close to our target of 120. Across the IPCHiP consortium, 515 families have participated. Rapid trio WGS has been implemented for all recruited participants, with a median turnaround time of 21 days. This represents the first large-scale implementation of rapid WGS outside intensive care for children with a rare disease and, therefore, demonstrates early evidence for the feasibility and scalability of this approach. Once complete, this will be the largest prospectively recruited paediatric epilepsy cohort for a genetic study to date.

We recently carried out a re-analysis of genome sequencing data from 176 infants whose initial tests did not provide a diagnosis, the findings of which have been accepted for publication in Neurology. Using novel bioinformatics pipelines, we identified 9 additional genetic diagnoses. These improvements included detecting structural changes in DNA, mosaic variants (where only some cells carry the change), and tandem repeat expansions. We also reclassified 3 previously uncertain variants as clinically significant using RNA sequencing and other functional tests. All of these findings had practical implications for patient care and management.

We have also longitudinally assessed the development of participants at baseline and at least one further timepoint. At each of these time points we collect data on development, motor skills, adaptive behaviour and quality-of-life, with language and social development added at the last time point. So far, 94 initial, 40 second, and 10 third assessments have been completed, generating critical evidence on the impact of early precision treatment.

To integrate phenotypic and genomic data, we have launched a unified REDCap database across four centres and partnered with DRIVE to extract demographic and research data from EPIC. A pilot project funded by the GOSH NIHR BRC is underway to analyse healthcare resource usage, enabling health economic comparisons between rapid and standard testing.

Finally, we are evaluating parent and carer experiences using the Parenting Stress Index and qualitative interviews at recruitment and subsequent visits. We have also interviewed care providers including doctors, nurses and laboratory staff regarding their experience of implementing rapid genetic testing. To date, 19 parents and 15 provider interviews have been completed and analysed thematically, offering insights that will inform best practices for counselling and implementation of rapid genetic testing.

Current projects

Workstream 1: Understanding Childhood Epilepsies

01 Gene-STEPS: Shortening Time of Evaluation in Paediatric epilepsy Services: a multi-centre prospective evaluation of the impact of early genetic diagnosis on patient outcomes

Project Aim: To implement rapid trio WGS for all children, utilise electronic healthcare records and research databases to unite phenotypic and genomic data and assess the impact of early genetic diagnosis on epilepsy, developmental, and health economic outcomes through formal longitudinal assessments of all children enrolled.
Investigators: Amy McTague, Helen Cross, Lyn Chitty, Neil Sebire
With: Annapurna Poduri (Boston Childrens), Katherine Howell, Ingrid Scheffer (Royal Childrens Hospital Melbourne), Gregory Costain, Vann Chau (The Hospital for Sick Children Toronto)

02 Is there an episignature in the rare epilepsies?

Project Aim: To understand the role of DNA methylation in rare epilepsies.
Investigators: Amy McTague, Manju Kurian

03 Understanding the role of vitamin B6 dyshomeostasis in epilepsy disorders

Project Aim: Establish and characterise zebrafish models of different genetic disorders of vitamin B6 metabolism associated with early onset epilepsy.
Investigators: Karin Tuschl, Philippa Mills, Richard Rosch, Isaac Bianco, Stephen Wilson

04 MELD Focal Epilepsies Project

Project Aim: To improve epilepsy surgery outcomes by developing Artificial Intelligence (AI) algorithms to automatically find subtle abnormalities on patients' MRI scans and help neurosurgeons to plan operations that will completely remove them.
Investigators: Sophie Adler, Konrad Wagstyl, Torsten Baldeweg, John Duncan, Juan Eugenio Iglesias, Helen Crosss

05 Transforming neurodevelopmental disorders using multi scale imaging and genomics

Project Aims:
- ✓ Develop computational tools to identify individual subject-level imaging abnormalities in neurodevelopmental disorders.
- ✓ Create a multiscale genetic, cellular and imaging framework for understanding the common and diverging neurobiological causes of epilepsy and ASD.
- ✓ Test the potential of these tools for linking genetics, imaging and phenotypes with known mutations in genes associated with epilepsy and autism.

Investigators: Konrad Wagstyl, Sophie Adler, Helen Cross, Finbar O'Callaghan, Amy McTague, Andreas Brunklaus, Armin Raznahan, Juan Eugenio Iglesias

06 The neuropathology of focal epilepsy in children

Project Aim: To understand the biology underlying the diseases that cause focal epilepsy.
Investigators: Tom Jacques, Helen Cross, Martin Tisdall, Darren Hargrave

07 Memory profile and reorganisation after epilepsy surgery in children with intractable Temporal Lobe Epilepsy (TLE)

Project Aim: To characterise the memory profile of children and young people and depict functional and structural reorganisation of memory networks in temporal lobe epilepsy before and after surgery, using functional magnetic resonance imaging (fMRI) and diffusion tensor imaging (DTI) magnetic resonance.
Investigators: Filipa Bastos, Faraneh Vargha-Khadem, Helen Cross, Jonathan Clayden, Sarah Buck

08 The genetics of early onset epileptic encephalopathy

Project Aim: The project aims to identify novel early onset epileptic encephalopathy genes which will contribute to the understanding of the disease mechanisms involved in such epilepsies.
Investigators: Amy McTague, Helen Cross, Dimitri Kullmann, Rod Scott, Manju Kurian

09 A natural history of Pyruvate Dehydrogenase Complex deficiency

Project Aim: To describe the natural history of Pyruvate Dehydrogenase Complex (PDC) deficiency from childhood to adulthood, including the spectrum of molecular diagnoses in affected patients.
Investigators: Nandaki Keshavan, Shamima Rahman

10 Novel network analysis of intracranial stereoelectroencephalography (SEEG)

Project Aim: To characterise interictal abnormalities in single unit neural dynamics and to establish whether the regions that display abnormal dynamics are consistent with the epileptogenic zone.
Investigators: Rod Scott, Martin Tisdall, Aswin Chari, Rachel Thornton

11 Landau-Kleffner syndrome: Patterns in the recovery phase

Project Aim: A retrospective case note review examining cognitive and language trajectories across different phases of Landau-Kleffner syndrome (LKS).
Investigators: Maria Clark, Gemma Wilson

12 EAGLET: EEG vs aEEG to improve the diagnosis of neonatal seizures and Epilepsy - a Randomised Trial

Project Aim: EAGLET is a prospective multicentre randomised controlled trial to evaluate whether the combination of cEEG with aEEG is superior to aEEG in the real time evaluation and diagnosis of neonatal seizures and in reducing time to treatment.
CIs: Ronit Pressler and David Rowitch
Co-investigators: Topun Austin, Paul Clarke, Claudia Chetcuti-Ganado

13 The Meerkat Project

Project Aim: The Meerkat project aims to develop non-contact monitoring for neonates in intensive care. A collaboration between the Departments of Engineering and Paediatrics at the University of Cambridge, as well as universities in the UK and Europe, the project will leverage expertise in image processing and machine learning to improve neonatal care.
CI: Kathy Beardsall
Co-investigators: Alex Grafton, Peter Marschik, Ronit Pressler, Oliver Bonner

14 Epilepsy in Infancy: relating phenotype to genotype (EPIPEG)

Project Aim: To identify and follow-up a cohort of children with new onset of epilepsy under 12 months of age to enable definition of neurobehavioral phenotypes; identify risk factors for neurodevelopment and later intellectual disability.
Investigators: Helen Cross, Manju Kurian, Rod Scott, Christin Eltze, Finbar O'Callaghan, Michelle De Haan, Elaine Hughes, Jane Kung, Manuela Pisch, Katy Barwick, Aikaterini Vezyroglou

15 Turning6 - A Clinical and Neurodevelopmental follow up of EpiPEG participants at 60 months

Project Aims:
- ✓ Characterise the neurodevelopmental (cognition, behaviour, sleep) status of children who had epilepsy in the first year of life.
- ✓ Examine the association between initial neurodevelopmental and clinical assessment results and performance at follow-up.
- ✓ Examine factors including epilepsy factors and neurodevelopmental status associated with current performance and changes in performance between initial assessment and follow-up.

Investigators: Colin Reilly, Finbar O'Callaghan, Manuela Pisch, Abigail Wooldridge, Lara Carr, and Helen Cross

16 SCN1A Horizon's: A natural history study of SCN1A related epilepsies in the UK

Project Aim: The SCN1A Horizons natural history study will establish a national UK platform for long term data collection on assessment and therapy of up to 400 child and adult patients with a genetically confirmed SCN1A variant. This study will increase our understanding of Dravet syndrome and SCN1A-related epilepsies by allowing us to learn more about the seizures, learning abilities and behavioural difficulties that children and adults with an SCN1A-related epilepsy live with.
Investigators: Andreas Brunklaus, Helen Cross, Amy McTague, Michael Absoud

17 FG12-related epilepsy: putting the brake on sodium channels

Project Aims:
- ✓ Establishing a patient-derived neuronal model of FGF12-epilepsy.
- ✓ nvestigating disease phenotypes in patient-derived neurons.
- ✓ Assessing novel therapeutic approaches to modulate FGF12.

Investigators: Amy McTague, Serena Barral, Gabriele Lignani

18 International guidelines for Pyruvate Dehydrogenase Complex Deficiency (PDCD)

Project Aim: To develop international consensus guidelines for the diagnosis and management of PDCD
Investigators: Prof Shamima Rahman (UCL GOS ICH) and Dr Jerry Bedoyan (University of Pittsburgh) Early career rep: Dr Nandaki Keshavan (UCL GOS ICH). In collaboration with 21 other experts from Europe and the USA and patient advocacy groups (The Freya Foundation, The Elizabeth Watt PDCD Research Fund, and Hope for PDCD).

19 Multimodal approach to investigate pathomechanisms and biomarkers for early diagnosis of Rasmussen Encephalitis

Project Aim: This project, based at Great Ormond Street Hospital and UCL, aims to understand what causes RE and to discover early warning signs (biomarkers) that could allow earlier diagnosis and treatment. Using advanced techniques such as DNA sequencing, transcriptomics, and antibody profiling, the applicant will study brain tissue, blood, and spinal fluid from affected children. These tools may reveal hidden genetic mutations, immune responses, or infections linked to the disease.
Investigators: Evangelia Ioannidou, Tom Jacques, Suresh Pujar, Marios Kaliakatsos, Helen Cross

Current projects

Workstream 2: Outstanding Treatment

20 The 7T Temporal Lobe Epilepsy Study

Project aim: The 7-TLE study is a prospective neuroimaging study that is using super-high-field (7-Tesla) MRI to investigate the network abnormalities in children and adults with temporal lobe epilepsy.
Investigators: Rory Piper, Shan-Shan Tang, Alexander Hammers, Atta Siddiqui, John Duncan, Martin Tisdall, David Carmichael, Torsten Baldeweg

21 Comprehensive neuroimaging characterization of neurodegeneration and brain plasticity in children with Rasmussen Syndrome

Project aim: The primary objective of the project is to identify predictors of successful cognitive recovery after surgical treatment.
Investigators: Torsten Baldeweg, Suresh Pujar, Patricia Sanfilippo, Marios Kaliakatsos

22 Dynamic variability in the epileptic brain

Project aim: Investigate how epileptic brain activity changes over time at multiple scales (seconds, minutes, days), in order to understand how our diagnosis and interventions can be targeted appropriately.
Investigators: Richard Rosch, Jamie Norris, Stuart Smith, Martin Tisdall, Gerald Cooray, Karl Fristo

23 The CADET Trial: The Children's Adaptive Deep brain stimulation for Epilepsy Trial

Project Aim: To determine the safety and feasibility of a novel non CE licensed DBS device for children with Lennox Gastaut Syndrome.
Investigators: Martin Tisdall, Helen Cross, Tim Denison, Harutomo Hasegawa, Elaine Hughes, Marios Kaliakatsos, Kei Landin, Rory Piper, Richard Selway, Antonio Valentin

24 Determining the utility of OPM-MEG in a clinical context

Project Aim: This project aims to fast-track regulatory approval of a new OPM-MEG system, making it the first, and only OPM-MEG system in the world to be approved for human use.
Investigators: Christine Embury, Zelekha Seedat, Kelly St Pier, Caroline Scott, Lara Carr, Dominic Sims, Elena Boto, Matt Brookes and Helen Cross

25 Modelling neuronal dysfunction in early onset epilepsies; a patient-centric approach

Project Aims:
- ✓ To create and characterise a patient-derived induced pluripotent stem cell (iPSC) organoid model in Epilepsy of Infancy with Migrating Focal Seizures (EIMFS).
- ✓ To investigate the neuronal phenotype of EIMFS at a cellular and network level.
- ✓ To investigate the impact of novel therapies.

Investigators: Amy McTague, B Cerna, E O'Connell, Gabriele Lignani, H Zhou, Manju Kurian

26 Is pyridox(am)ine 5'-phosphate oxidase deficiency, an eminently treatable cause of epilepsy, under-recognised in children?

Project Aim: To improve diagnosis and treatment of children with pyridox(am)ine 5'-phosphate oxidase (PNPO) deficiency by using a novel rapid screening dry blood spot assay.
Investigators: Peter Clayton, Philippa Mills, Helen Cross, Ronit Pressler

27 The Diagnosis and Management of Pyridoxamine 5'-Phosphate Oxidase Deficiency

Project Aim: To create guidelines for the diagnosis, treatment and follow up of Pyridoxamine 5'-Phosphate Oxidase Deficiency which will facilitate clinical decision making and improve the care for patients with PNPO-deficiency in a standardised manner.
Investigators: Philippa Mills and Emma Footitt

28 Improved diagnosis and monitoring of treatment for patients with epilepsy caused by mutations in ALDH7A1

Project Aim: To work out the most reliable compound for detection of ALDH7A1-deficiency which could be used for newborn screening.
Investigators: Philippa Mills, Emma Footitt, Helen Aitkenhead, Peter Clayton, Alistair Horman, Youssef Khalil

29 Optimisation and bioperformance of a novel formulation of pyridoxal 5'-phosphate for treatment of pyridox(am)ine 5'-phosphate oxidase deficiency induced epilepsy in children

Project aim: To test the performance in the lab and in vivo of an improved pyridoxal 5'-phosphate (PLP) option for children with pyridox(am)ine 5'-phosphate oxidase deficiency induced epilepsy.
Investigators: Catherine Tuleu, Peter Clayton, Philippa Mills, Emma Footitt, Ahad Rahim, Simon Heales

30 Cooling in Mild Encephalopathy Trial (COMET)

Project Aim: The goal of this randomised control trial is to evaluate the safety, efficacy, and cost-effectiveness of whole-body hypothermia as a therapy for babies with mild HIE.
Investigators: Prof Sudhin Thayyil, Seetha Shankaran, Dr Ronit Pressler, Prof Andrew Shannon, Dr Kerry Woolfall, Prof Samantha Johnson, Prof Patricia Grant, Dr Farah Alobeidi, Prof Stavros Petrou, Mrs Sarah Land, Mrs Mariam Mahmoud, Ms Stuti Pant, Mr Paul Basset, Mr Tony Brady, Prof Victoria Cornelius, Dr Aung Soe, Dr Eleri Adams, Prof Jon Dorling, Dr Ella Chakkarapani, Dr Balamurugan Palanisami, Dr Paolo Montaldo

31 Functional brain connectomics: implications for post-surgical outcomes in children with focal epilepsy

Project Aim: In this project we will estimate how strongly seizure generating parts of the brain (the surgical target zones) are connected to other, healthy parts of the brain.
Investigators: Xiyu Feng, Jon Clayden, Torsten Baldeweg, Rory Piper

32 Reconstruction and Computational Modelling for Inherited Metabolic Diseases [Recon4IMD]

Project Aims: Using personalised computational modelling to:

- ✓ Accelerate the diagnosis of patients at risk of an inherited metabolic disorder [IMD].
- ✓ Refine the diagnosis of patients at risk of an IMD.
- ✓ Stratify IMD patients by clinically actionable compensatory and aggravating metabolic mechanisms that associate with phenotypic severity.

Investigators: Professor Shamima Rahman [UCL is one of 12 participating organisations in this Horizon Medicine grant being coordinated by Professor Ronan Fleming at the University of Galway]

33 Gene therapy for deoxyguanosine kinase deficiency

Project Aim: To develop a gene therapy for deoxyguanosine kinase deficiency, a fatal mitochondrial disease of infancy.
Investigators: Shamima Rahman
Co-investigators: Nandaki Keshavan. Simon Waddington, Rajvinder Karda, Mario Cortina-Borja

34 Minimally invasive self-regulating gene therapy for neuropsychiatric disorders

Project Aim: Many neuropsychiatric disorders involve episodic symptoms arising from unstable brain circuits that become hyperactive, leading to seizures, psychotic episodes, or accelerated cognitive decline. Rather than targeting symptoms, we aim to address the underlying circuit instabilities by developing cell-state specific gene therapy that modulates only overactive neurons while sparing normally functioning ones.
Investigators: Gabriele Lignani, Dimitri Kullmann, Jerzy Szablowski, Mikhail Shapiro, Richard Rosch

35 Neurological digital twins: precision surgical planning of epilepsy treatment

Project Aim: The aim of this project is to develop precision digital twins of human brain function to tailor surgical intervention for focal epilepsies. This will involve:

- ✓ Development of novel geometric-deep learning technologies that simulate human brain functional dynamics in response to stimuli.
- ✓ Precisely the sites of epileptogenic brain lesions.
- ✓ In silico trials of surgical treatment.

Investigators: Emma Robinson, Joel Winston, David Carmichael

36 7 Tesla Sodium MRI for Identifying Focal Brain Lesions Causing Paediatric Epilepsy.

Project Aim: To explore the utility of sodium MRI as a structural and functional biomarker in paediatric focal epilepsy patients.
Investigators: Jon Cleary, Jonathan O'Muircheartaigh, Ozlem Ipek, Alexander Hammers, Shaihan Malik, David Carmichael

Current projects

Workstream 3: Outstanding Support

37 Epilepsy Carers Uniting with Researchers (E-Cure) PPI network

Project Aim: Strengthen the voice of children and young people with epilepsy in our research by establishing the UKs first network of parents, carers and young people who volunteer to shape childhood epilepsy research.
Investigators: Lara Carr, Susi Khan, Samantha Chan, Amy McTague, Helen Cross

38 Epilepsy Pathway Innovation in Africa (EPInA)

Project Aims:

- **Societal change:** Ensure an enduring, positive change by improving public awareness and reducing the stigma experienced by people with epilepsy in sub-Saharan Africa.
- **Diagnose:** To improve the rate of accurate diagnosis of epilepsy by primary health care workers with app-based technologies.
- **Treatment:** Increase the adherence to medication using text messaging.
- **Prevent:** Reduce the incidence of infection and peri-natal injury in an endemic region in Tanzania and the subsequent risk of epilepsy.

Investigators: Charles Newton, Arjune Sen, Helen Cross, Josemir Sander, Albert Akpalu, Patrick Adjei, Symon Kariuki, Damazo Kadengye, Gershim Asiki, Thomas Kwasa, Bruno Mmbando, Dan Bhwana, Tarun Dua, William Matuja, Sloan Mahone, David McDaid, Richard Walker

39 European Reference Network on rare and complex epilepsies (EpiCARE)

Project Aims:

- To improve accessibility of detailed diagnostics to individuals of all ages with rare and complex epilepsies across Europe, including clinical evaluation and investigation.
- To develop treatment protocols and monitor standardised outcomes of rare and complex epilepsies.
- To improve awareness and accessibility to protocols for physicians and individuals with rare and complex epilepsies across Europe for treatment.
- To enhance educational activities and training opportunities across Europe by interchange across the network.
- To enhance opportunities for registries, and collaborative research for the benefit of individuals with rare and complex epilepsies across Europe.

40 Prevention of Epilepsy by reducing Neonatal Encephalopathy (PREVENT) study

Project Aim: To examine a care bundle approach to improve the maternal care around delivery to reduce number of babies sustaining serious birth related brain injury and epilepsy.
Investigators: Sudhin Thayyil, Helen Cross, Ronit Pressler, and many more

41 Assessment of profound intellectual disability in complex epilepsy

Project Aim: To develop a robust assessment tool for children with complex epilepsy.
Investigators: Maria Clark, Gemma Wilson, Steve Rose, Karen Ray

42 Physical Activity in Primary School-Aged Children with Epilepsy (PACE - Prime)

Project Aim:

- Conduct a prospective observational study to compare levels of Physical Activity (PA), sedentary behaviour and sleep in primary school-aged children with and without epilepsy using accelerometers and survey methods.
- Identify factors associated with levels of PA, sedentary behaviour and sleep in primary school aged Children with Epilepsy (CWE).
- Explore CWE, parental and school staff views on barriers/facilitators for CWE engaging in PA.

Investigators: Colin Reilly, Natalie Pearson, Lauren Sherar, Monica Lakhanpaul, Kerry Robinson, Lara Carr, Helen Cross

43 Acceptance & Commitment Therapy (ACT) in Children and Young People with epilepsy

Project Aims: To develop, deliver, and evaluate ACT-based intervention groups and self-help resources to improve mental health support for young people with epilepsy and their families in the UK.
Investigators: Natasha Hughes, Emily Rhidian, Lara Carr, Alexander Marsh, Ingram Wright

44 Epilepsy in Schools: Developing web-based training for educational staff who support children with epilepsy in mainstream schools

Project Aims: The overall aim of this project is to develop, pilot and assess the feasibility of web-based interventions for staff currently supporting children with epilepsy. The specific aims of this project are to:

- Co-develop web-based training for teachers and other educational staff who support children with epilepsy in mainstream schools.
- Conduct a pilot study of the developed web-training focusing on the knowledge and attitudes of educational staff in mainstream schools before and after the training.

Investigators: Collette Meades, Joan Idowu, Bhavna Sidhpara, Lara Carr, Helen Cross, Colin Reilly

45 Transition from paediatric healthcare to adult healthcare for young people with epilepsy in the UK: A scoping review and focus group study

Project Aim:

- To identify and synthesize published research on transition from pediatric to adult healthcare for Young People with Epilepsy (YPE) in the UK.
- To conduct focus groups with young people with epilepsy and caregivers to better understand experiences of transition.
- To understand the experiences and needs of health care professionals who work with young people with epilepsy during the transition process.

Investigators: Joe Paternoster, Abigail Wooldridge, Rainne Gooselink, Lara Carr, Helen Cross, Colin Reilly

Completed projects

Workstream 1: Understanding Childhood Epilepsies

46 Multicentre Epilepsy Lesion Detection (MELD) Project

Project Aim: Create open-access, robust and generalisable tools for understanding and detecting focal cortical dysplasias (FCDs) that can assist the pre-surgical evaluation of patients with drug resistant epilepsy.
Investigators: Sophie Adler, Mathilde Ripart, Hannah Spitzer, MELD consortium, Helen Cross, Torsten Baldeweg, Konrad Wagstyl

47 Management of seizures in patients with primary mitochondrial diseases: Consensus statement from the InterERNs Mitochondrial Working Group

Project Aim: We aim to develop guidelines and consensus recommendations on safe medication use and seizure management in mitochondrial epilepsy using Delphi methodology.
Investigators: Michelangelo Mancuso, Maria T Papadopoulou, Yi Shiau Ng, Anna Ardissone, Marcello Bellusci, Enrico Bertini, Lidia Di Vito, Teresinha Evangelista, Carmen Fons, Omar Hikmat, Rita Horvath, Thomas Klopstock, Cornelia Kornblum, Costanza Lamperti, Laura Licchetta, Maria Judit Molnar, Kristin N Varhaug, Mar O'Callaghan, Ronit M Pressler, Manuel Schiff, Serenella Servidei, Nora Szabo, Gráinne S Gorman, Helen J Cross, Shamima Rahman

Workstream 2: Outstanding Treatment

48 Realising the potential of 7T MRI for paediatric imaging

Project Aim: To enable the first 7 Tesla (7T) magnetic resonance imaging (MRI) of paediatric patients with epilepsy being evaluated for surgery at GOSH and Kings College London Hospital (KCLH).
Investigators: David Carmichael, Helen Cross, Martina Callaghan, Shaihan Malik, Thomas Booth, Sila Dokumaci, Fred Dick, Dr Simon Richardson, Serena Counsell, Alex Hammers, Jonathan O'Muircheartagh

49 The fast without the spurious: developing a system for robust and rapid simultaneous EEG-fMRI measurements

Project Aim: To develop more advanced EEG-fMRI scans that may better detect brain areas active at the start of seizures. To do this we are trying new motion-correction technology that tells the scanner where the head is using camera and a marker attached to a dental retainer and updates the scanner accordingly.
Investigators: Amy McDowell, Danilo Maziero, David Carmichael, Helen Cross, Kelly St Pier, Nikolaus Weiskopf, Mirja Steinbrenner

50 The "Pair Test": an App to diagnose learning and memory impairments in children with Temporal Lobe Epilepsy

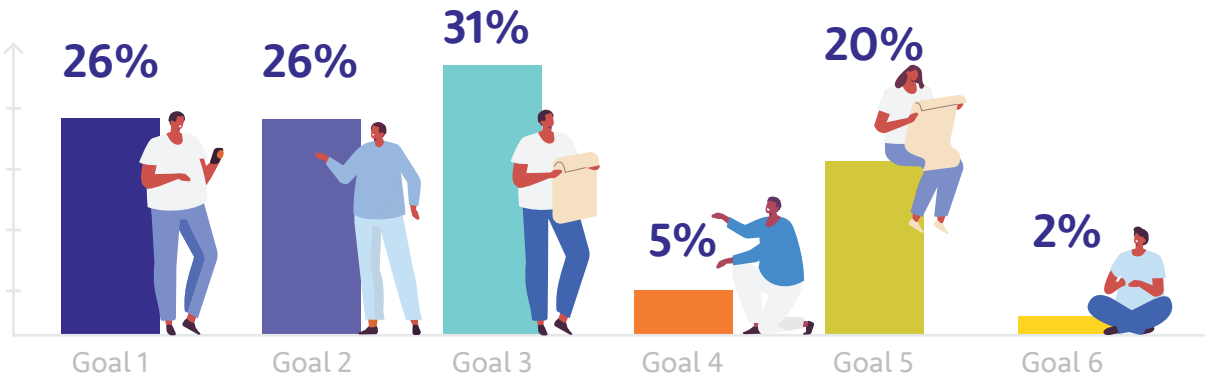
Project Aim: To provide better informed diagnosis of memory impairments in children with epilepsy and predict outcome after surgery in the temporal lobe, using the Pair Test.
Investigators: Sarah Buck, Torsten Baldeweg, Filipa Bastos, Faraneh Vargha-Khadem

Impact of our research

Young Epilepsy

Current and Past Impact

Between July 2024 and June 2025 the programme portfolio consisted of

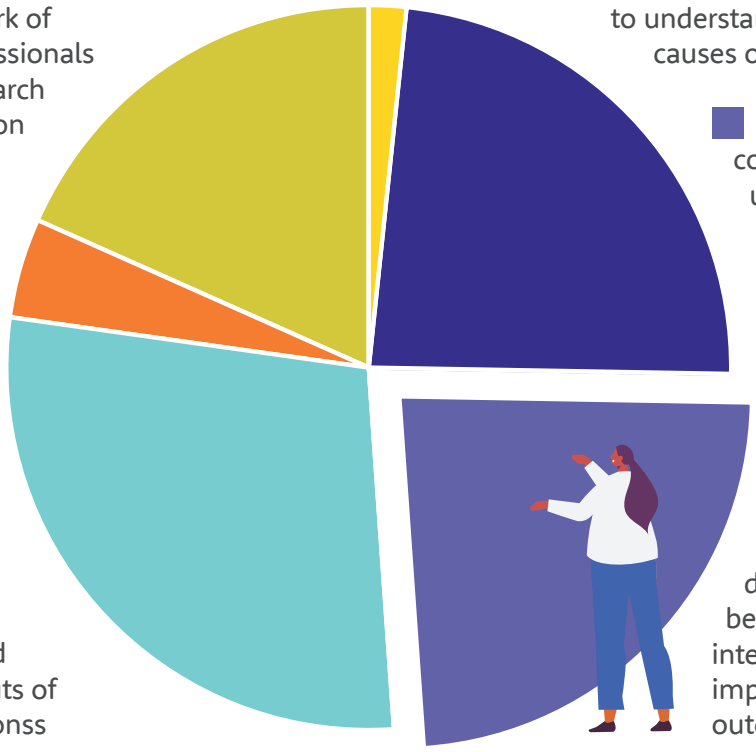


contributing to each goal respectively

2% of projects contributed to developing a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners

20% of projects contributed to making life better for children and families and making support systems more effective

5% of projects contributed to understanding the barriers to learning and determining the benefits of educational interventionss



26% of projects contributed to understanding the medical causes of epilepsy

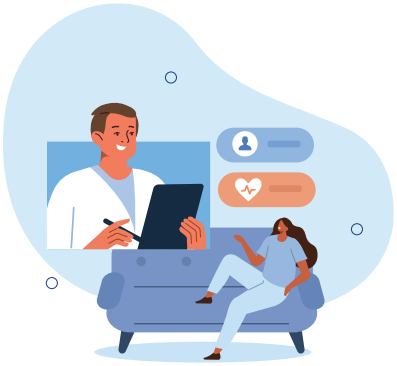
26% of projects contributed to understanding how epilepsy affects development and behaviour

31% of projects contributed to improving diagnosis and treatment to determine the benefits of early intervention in improving long-terms outcomes

Year on year most of our projects address:

Workstream 1
Understanding
Childhood
Epilepsies

Workstream 2
Outstanding
Treatments



But we are growing our work in:

Workstream 3
Outstanding Services

96
published
peer-reviewed items of primary research

26
reviews

Specialist PPI network for childhood epilepsy with over

217
members

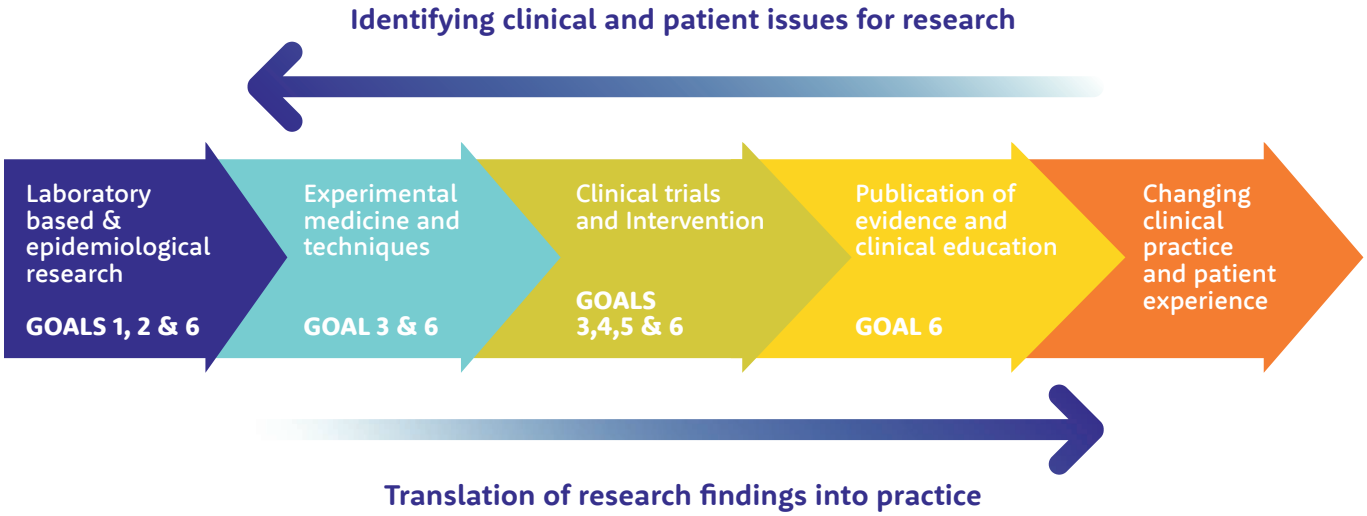
The Annual Research Retreat had almost

100
attendees

Meeting our research goals

Our research begins with identifying real clinical challenges and listening to feedback from patients. These insights are transformed into project plans, for which we seek funding and bring together expert teams.

The ultimate goal is to publish findings as original research that has undergone rigorous peer review by independent specialists. This process ensures that the evidence we generate is robust, enabling us to implement meaningful changes and guide future research.



In 2024/25, we had 48 active research projects (Figure 1), continuing the upward trend since 2022 and approaching pre-Covid levels. Each project is mapped to our three workstreams and six strategic goals (Figure 2). Historically, our strengths have been in Workstream 1: Understanding Childhood Epilepsies and Workstream 2: Outstanding Treatments (Figure 3). At the same time, we are expanding our focus on Workstream 3: Outstanding Support, driving educational, psychosocial, and service-based research to improve support for individuals and families living with epilepsy.

Figure 1: Number of active research projects per year

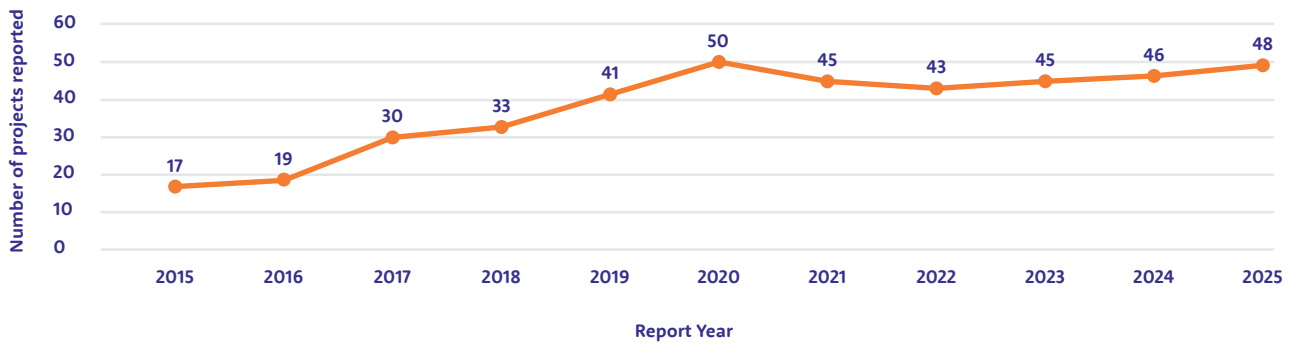
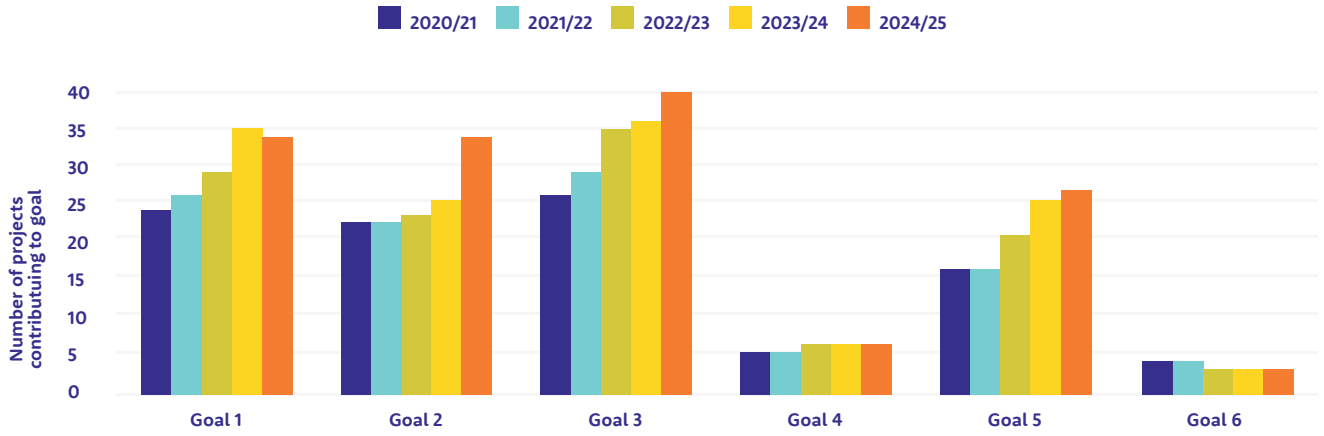


Figure 2: Number of active projects contributing to each goal

Many projects contribute to more than one workstream and/or goal



The strength of the evidence we publish

Over the past 11 years, our research programme has grown significantly from having just four Principal Investigators (the leaders of research units and laboratories, often Professors), to 32 Principal Investigators supervising 35 PhD students and collaborating with an additional 30 international researchers (Figure 4).

2025 has seen another notable rise in the publication of original research (Figure 5), marking a strong recovery to pre-COVID-19 levels. Although there has been a slight decline in published reviews and books, the overall number of publications has risen. This upward trend, combined with the increasing number of active projects, indicates that our research output is set to expand further in the coming years.

Figure 4: Annual growth of the Research Unit Network

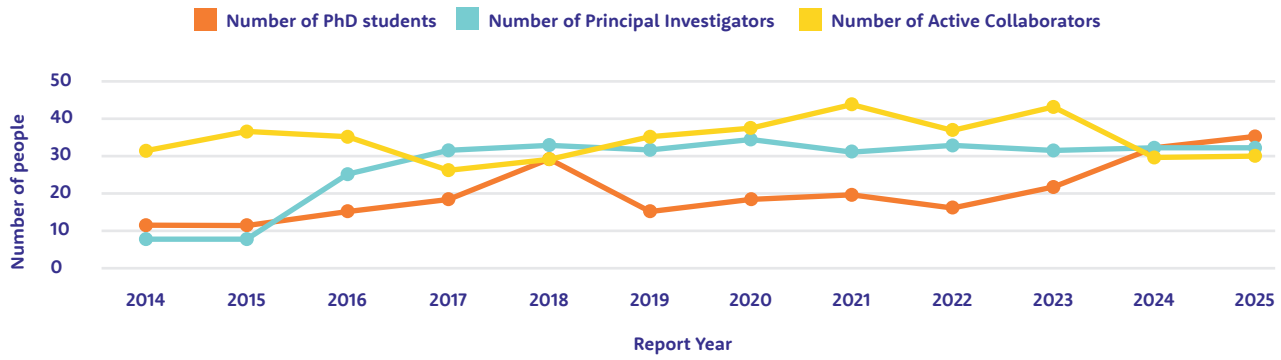
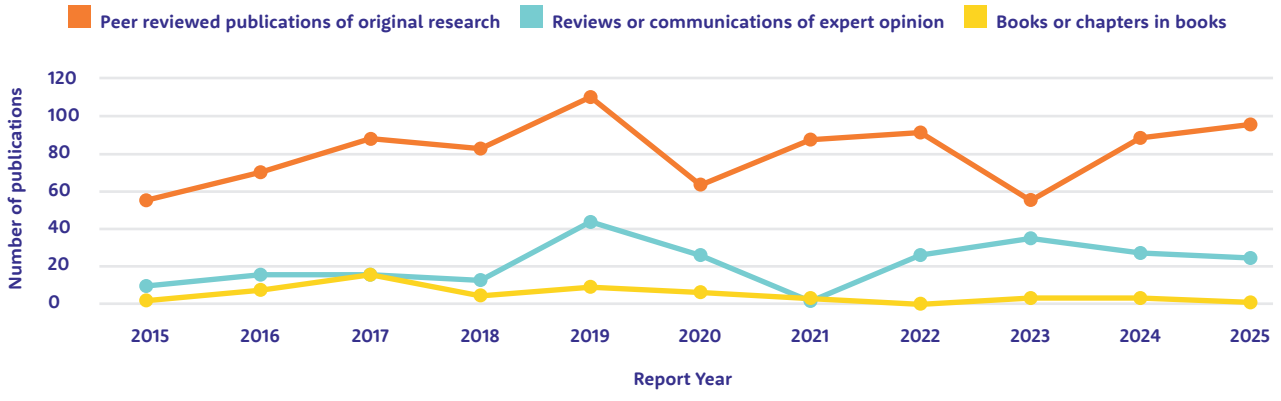
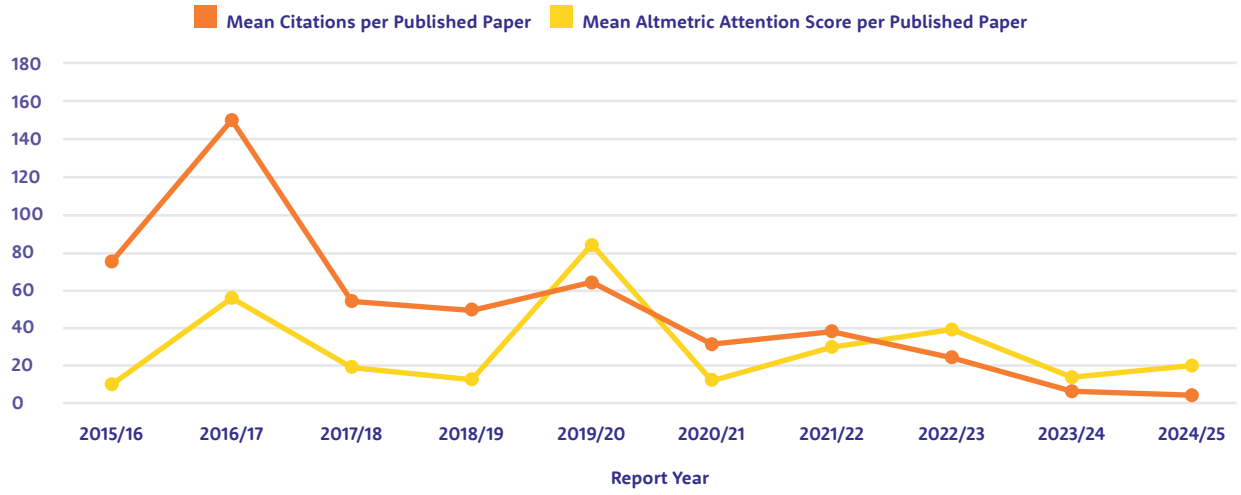


Figure 5: Number of research publications produced per year



We track the progress and influence of these research publications over time using two metrics – citations and an altmetric attention score (Figure 6). A citation is counted when an individual research paper is referred to in a later research publication as a source of evidence. The altmetric attention score that we use is produced by an independent bibliographic data organisation, Dimensions.ai, and is calculated based on the public attention that an individual publication has received across news articles, social platforms, and policy documents.

Figure 6: Impact of research publications



This year's publications have been cited less frequently than those from previous years, which is expected given that citations typically accumulate over time. Compared to 2023/34, however, there has been a slight rise in Altmetric Score, suggesting that recent publications may have attracted more immediate attention (Figure 6).

Overall, we have achieved strong impact, with 5 papers receiving an Altmetric score of over 100, placing them in the top 5% of all research outputs tracked by ReadCube. This is comparable to last year, which also saw five such high-scoring publications.

Topics of the 2024/25 high impact papers cover:

- A study demonstrating the use of graph neural networks to detect epileptogenic focal cortical dysplasia from MRI data, offering a novel AI-driven approach to improve diagnosis in drug-resistant epilepsy.
- A position paper outlining the updated International League Against Epilepsy classification of epileptic seizures, providing a refined framework to standardise terminology and improve diagnostic accuracy, clinical management and research.
- A study which used data from the 100,000 Genomes Project to uncover new links between genes and rare diseases, helping improve understanding of these conditions and paving the way for better diagnosis and personalised treatments.
- A study examining long-term neuropsychological outcomes in children with epilepsy, evaluating whether surgical intervention stabilises or halts cognitive decline over time.
- A review providing an in-depth overview of developmental and epileptic encephalopathies, highlighting their genetic basis, clinical features, diagnostic approaches, and emerging treatment strategies to improve outcomes for affected individuals.

Importance of PPI

Our collaboration with Great Ormond Street Hospital and the UCL Institute of Child Health ensures that our research priorities are driven by real clinical needs. Central to this approach is listening to everyone affected by epilepsy research. This not only includes researchers and consultants, but also nurses, support workers, caregivers, parents, and, most importantly, young people themselves.

Patient and Public Involvement (PPI) is the practice of involving patients and the public in shaping research. It is essential for creating studies that are practical, relevant and meaningful. At Young Epilepsy, PPI is central to our research.

How we involve families and young people

Epilepsy in childhood:
Carers
Uniting with
REsearchers
...join the conversation"

E-CURe Network (Epilepsy Carers Uniting with Researchers)

This network brings together parents and caregivers of children with epilepsy alongside dedicated researchers, ensuring their voices influence the future of epilepsy research. We currently have 217 members and are keen to welcome more. See page 48 for details on how to join.

Youth Voice Network

We also work closely with our Youth Voice Network to ensure that the voices of children and young people are represented in our research. The Youth Voice Network is a group of over 200 young people with epilepsy, between the ages of 13-25, who help to ensure that young people are at the centre of everything we do at Young Epilepsy. To find out more and get involved:

www.youngepilepsy.org.uk/get-involved/give-time/be-member-youth-voice-network

Making a Difference

Over the past year, these networks have played a vital role in several projects. Two highlights include:

Digital Health Passport for Epilepsy

Through an SBRI-funded project, we partnered with Tiny Medical Apps to inform the development of a Digital Health Passport for epilepsy. This free self-management app, originally designed for asthma and allergies, is being expanded to include epilepsy-specific modules. Young Epilepsy has led on PPI, ensuring trusted content and shaping features such as emergency plans, medication support, and seizure and mood tracking. Regular PPI and clinical expert groups feed directly into quarterly updates, helping ensure the app tackles real challenges in ways that truly fit families' needs.

Acceptance and Commitment Therapy (ACT) for young people and their caregivers

We have co-produced an ACT-based group intervention, tailored to support the mental health needs of young people with epilepsy. A toolkit of resources including a manual, slides, and workbook was developed, embedding epilepsy-specific psychoeducation and lived experience examples. The programme has been delivered across NHS Trusts, and we are now evaluating its feasibility, acceptability and impact on mental health outcomes. We are also developing a companion programme for caregivers and a self-help version for our website. Feedback from a parent involved in co-production:

> *My daughter was diagnosed with epilepsy when she was 13. I've been desperate to learn more ever since and jumped at the chance to join Young Epilepsy's Parenting Plus group. Around six of us meet online to share ideas about what support carers need. It's a constant battle to navigate each challenge my daughter faces, so it's great to work on something that will give parents and carers more help.*

Top 10 Epilepsy Research Priorities

As we have previously reported, Young Epilepsy were honoured to be part of the UK Epilepsy Priority Setting Partnership (PSP) in partnership with Epilepsy Research UK.

The UK PSP were tasked with investigating the health priorities of people with Epilepsy. A survey, completed by 2,014 individuals, identified approximately 5,418 research priorities. From these 110 research questions were drafted, of which 57 were moved forward for prioritisation. 25 of these were shortlisted for discussion at the UK Epilepsy PSP workshop, with the aim of selecting the top 10 priorities for Epilepsy research. The selected Top 10 Epilepsy Research Priorities were:

01 What are the causes and contributing factors of epilepsy-related deaths, including Sudden Unexpected Death in Epilepsy (SUDEP), and how can these deaths be prevented?

02 What underlying mechanisms cause epilepsy in children and adults?

03 What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health – including, cognition, memory, learning, behaviour, and mental health?

04 How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented?

05 How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy?

06 How can tools, devices and biological markers be used to accurately predict and prevent seizures and the onset of epilepsy?

07 How do hormonal changes in women throughout the lifespan (e.g., puberty, pregnancy, menopause) impact epilepsy, and how can this impact be addressed?

08 How can quality of life be improved for people with epilepsy, their family and carers, including those bereaved by epilepsy?

09 What causes drug-resistant (refractory) epilepsy, and how can it be best treated?

10 How can big data analysis, through artificial intelligence (AI) and machine learning, aid the diagnosis and management of epilepsy?

Creating clearly defined research priorities with input from the entire epilepsy community, allows future research to concentrate on the research areas that matter most.

With this in mind, we have mapped our current studies by their project number onto each of the ten priorities (a project can address more than one priority). At present we are addressing all but two of the priorities, and the majority of our work is focussed on priorities 2, 3, 4, 6. This is unsurprising given that our work is focussed on paediatrics and, in particular, understanding and treating childhood epilepsies.

Young Epilepsy Paediatric Epilepsy Research Retreat 2025

The Young Epilepsy Research Retreat, led by The Prince of Wales's Chair of Childhood Epilepsy, is an annual event that brings together leading researchers, clinicians, and collaborators to share insights and shape the future of childhood epilepsy research.

Our 2025 retreat marked a significant milestone, the 15th annual Retreat, welcoming close to 100 attendees over two days. The programme showcased 26 high-quality presentations spanning our diverse research portfolio, with highlights including the Turning Six and OPM-MEG projects. Each session was followed by engaging discussions, offering presenters constructive feedback from peers and principal investigators across multiple disciplines.

This year's retreat was chaired by Professor Helen Cross, and moderated by Professor Nicola Specchio, Chair of Neurology at the Epilepsy and Movement Disorders Unit at Bambino Gesù Children's Hospital, and Director of the Research Unit on Neurological and Neurosurgical Diseases in Rome, Italy.

The event remains a key opportunity for collaboration, with attendees valuing the opportunity to network, exchange ideas and strengthen partnerships. Feedback from attendees reinforces its role in advancing research across all aspects of childhood epilepsy.

Let's Talk About Epilepsy

The Young Epilepsy Podcast

In 2025, Young Epilepsy also launched its podcast – Let's Talk About Epilepsy – offering listeners real stories, expert insights, and honest conversations about life with epilepsy.

The series has already featured researchers from across our partnership and beyond, with many more episodes in development. Highlights include an in-depth discussion with Dr Sophie Bennett on the Mental Health in Childhood Epilepsy Project, alongside a broader conversation exploring the impact of epilepsy on mental health and how healthcare professionals can integrate mental health support into epilepsy care.

Other episodes have delved into the evolving landscape of treatment, from promising new medicines in paediatric care to the challenges posed by medication shortages, and examined how emerging technologies, such as AI, are creating new opportunities and hope for young people living with epilepsy.

Research Funding

Central to the research programme is the ability to apply for and manage research grants and other charitable donations.

Our collaborative funding strategy has enabled us to build the world's largest paediatric epilepsy research unit and network of multidisciplinary practitioners.

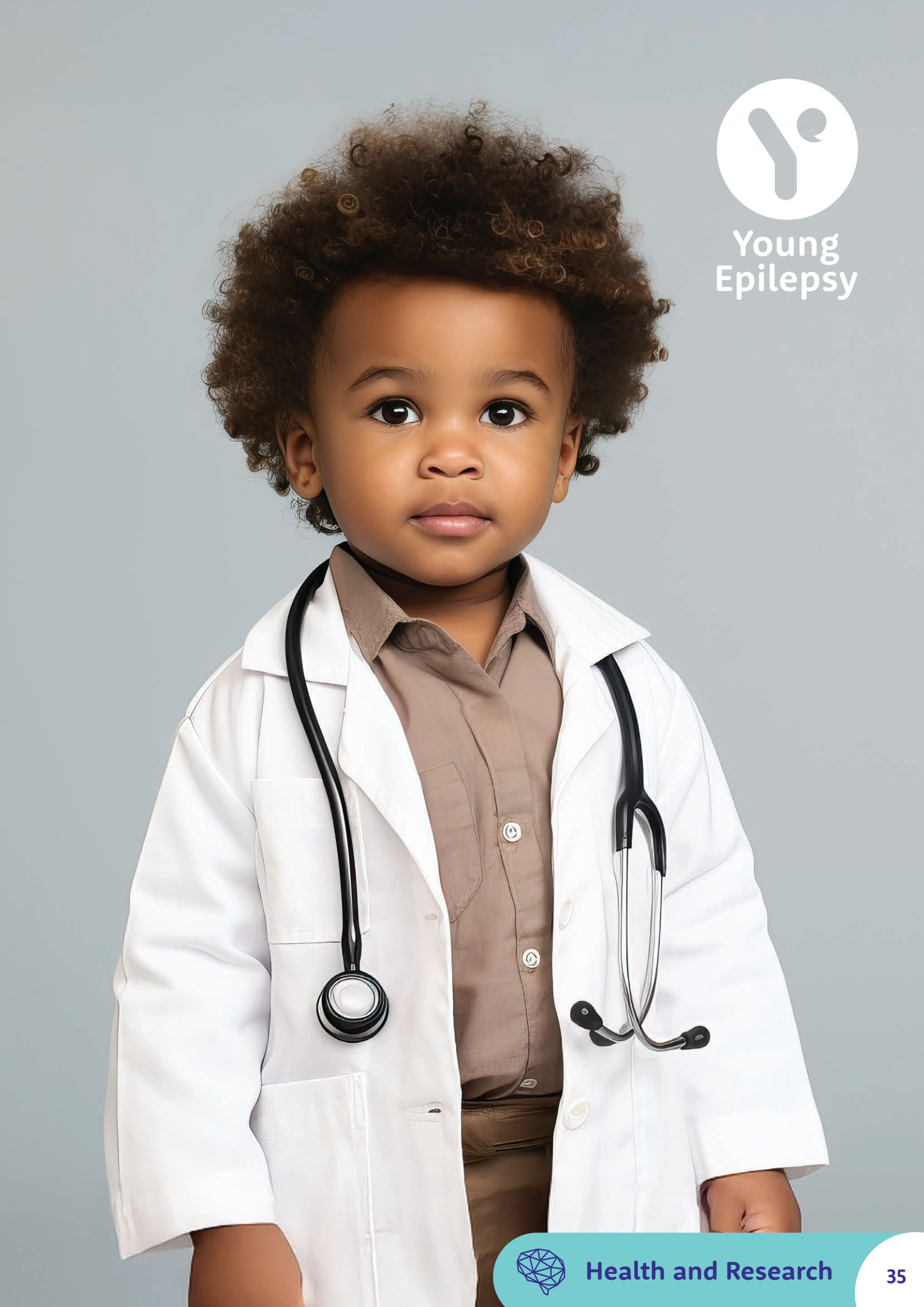
Alongside academic grants raised by the researchers and their academic institutions, we rely on the additional multidisciplinary fundraising by Young Epilepsy, which allow us to redirect funds where the need is greatest within a project. This flexibility is vital and provides stability during challenges, such as delays due to unforeseen circumstances.

The future of this programme rests on the ability to maintain and build the current infrastructure which allows us to maintain a base of operations to lead, coordinate and provide governance.

Action Medical Research
Angelini Pharma
Anna Mueller Grocholski Foundation
Autistica
Brain Tumour Charity
BRC Cambridge
Cancer Research UK
Child Health Research Charity
Children with Cancer UK
Desitin
Epilepsy Research Institute
Evelyn Trust
George E Neville Foundation
GOSH NIHR BRC
Great Ormond Street Children's Charity
Horizon Medical
Human Brain Project
Innovate UK
Jazz Pharma
Livanova
Medical Research Council Clinician Scientist Fellowship
National Institue of Health Research (HTC)
Neuraxpharm
Nevilles PLC
Nutricia
Oakgrove Foundation
Persyst
Rosetree's Trust
SBRI Healthcare

We remain ever grateful for the generosity and dedication of the organisations and individuals who support out work. Thank you! To find out how you can get involved in our vital work, visit:

www.youngepilepsy.org.uk/get-involved



Young Epilepsy

Researchers

The research team contribute to a wide spectrum of activities from basic science to patient care. The team consists of a multidisciplinary range of experts working across Young Epilepsy, UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children.

Principal Investigators

Professor Helen Cross OBE
The Prince of Wales's Chair of Childhood Epilepsy and Director UCL GOS - ICH

Young Epilepsy; UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children

Additional Roles:
Elected President (2021-2025) International League Against Epilepsy (ILAE)
Chair Research Council - European Reference Network for Rare and Complex Epilepsies (EpiCARE)
President - Epilepsy Research Institute UK
Clinical Advisor - Children's Epilepsy Surgery Service (CESS)
Clinical Advisor - Epilepsy Action
Chair of Medical Board - Hope for Hypothalamic Hamartoma
Chair of Medical Board - Matthew's Friends
Chair of the Medical Board - Dravet UK
Associate editor Brain Communications
Editorial Board Epilepsy Research
Chair – C4C neuroscience expert group
Chair – International Neurological Ketogenic Society

Dr Patricia Atkinson
Consultant Community Paediatrician

Sussex Community NHS Foundation Trust

Dr Sarah Aylett
Consultant Paediatric Neurologist

Great Ormond Street Hospital for Children

Additional Roles:
Caldicott Guardian Postgraduate Teaching - ICH-UCL

Professor Torsten Baldeweg
Professor of Developmental Cognitive Neuroscience, Head of UCL GOS - ICH Developmental Neurosciences Programme

UCL GOS - Institute of Child Health

Additional Roles:
Theme Lead – Capacity Building, Epilepsy Research Institute UK
Chairman of Exam Board, MSc Paediatric Neuropsychology - University College London
Module organiser and lecturer, MSc Paediatric Neuropsychology - University College London

Professor Gareth Barnes
Head of Magnetoencephalography

Department of Imaging Neuroscience, UCL

Dr Stewart Boyd
Consultant Clinical Neurophysiologist

UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children

Dr David Carmichael
Professor of MRI

School of Biomedical Engineering and Imaging Sciences, King's College London

Additional Roles:
Honorary Reader in Neuroimaging and Biophysics, Reader in Magnetic Resonance Physics
UCL GOS - Institute of Child Health and Wellcome/EPSRC Centre for Medical Engineering, Kings College London

Professor Chris Clark
Professor of Imaging and Biophysics, Head of UCL GOS – ICH Developmental Imaging and Biophysics Section

UCL GOS - Institute of Child Health

Dr Maria Clark
Consultant Paediatric Neurologist

UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children

Dr Felice D'Arco
Consultant Paediatric Neuroradiologist

Great Ormond Street Hospital for Children

Additional Roles:
Chair - GOSH MRI Safety Group
Honorary Senior Lecturer - UCL GOS - ICH and UCL Institute of Neurology
Lecturer - European Course of Paediatric Neuroradiology
Member - European Network for Brain Malformations
Member of the Editorial Board - Journal of the European Society of Neuroradiology

Professor Michelle De Haan
Professor in Infant and Child Development

UUCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children

Additional Roles:
Affiliated Scientist - British Autism Study of Infant Siblings Network
Course Speaker, MSc in Cognitive Neuroscience, Translational Research Module - University College London
Deputy Director, MSc in Clinical & Applied Paediatric Neuropsychology - UCL GOS - ICH
Director, MSc in Infancy and Early Childhood Development - UCL GOS - ICH
Membership of Steering Committees - Centre for Developmental Cognitive Neuroscience UCL
Membership of Steering Committees - Centre for Developmental Cognitive Neuroscience UCL

Dr Krishna Das
Consultant Paediatric Neurologist

Young Epilepsy and Great Ormond Street Hospital for Children

Professor Michelle De Haan
Professor in Infant and Child Development

UCL GOS - Institute of Child Health and Great Ormond Street Hospital for Children

Additional Roles:
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Course Speaker, MSc in Cognitive Neuroscience, Translational Research Module - University College London

Deputy Director, MSc in Clinical & Applied Paediatric Neuropsychology - UCL GOS - ICH

Director, MSc in Infancy and Early Childhood Development - UCL GOS - ICH

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Editor in Chief - Journal of Neuropathology and Applied Neurobiology

Lead - Paediatric Tumour Genomics England Clinical Interpretation Partnership (GeCIP)

Pathology representative on the Central Nervous System subgroup - National Cancer Research Institute (NCRI) Children's Cancer and Leukaemia Clinical Studies Group

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Scientific Adviser - KCNT1 Epilepsy Foundation

Member of Epilepsy Research Institute UK Scientific Advisory Committee and member of Advanced Therapeutics Task Force

Member of ILAE Genetic Literacy Task Force

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Additional Roles:

President - British Paediatric Neurology Association (BPNA)

Secretary and Board Member- European Paediatric Neurology Society (EPNS)

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Council member of the ILAE UK Branch

Course Director, EEG in the First Year of Life teaching course – ILAE

Associated Editor for Epilepsia Open

Member of the Editorial Board of European Journal of Paediatric Neurology and Neurophysiologie Clinique

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Web based teaching: e-brain and VIREPA (paediatric EEG)

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Editor-in-Chief - Journal of Inherited Metabolic Disease

Coordinator of Mitochondrial Subnetwork - Metabolic European Reference Network (MetabERN)

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Additional Roles:

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The role of vitamin B6 in health and disease

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Sudden Unexpected Death in Childhood; characteristics, autopsy findings and investigation

Dominic Burrows
Brain-wide abnormal dynamics during epileptic seizures at single cell resolution

Barbora Cerna
Epilepsy in 3D: investigation of a novel RNA-based therapy in cerebral organoids

Dimitrios Champsas
Improving the understanding of FIRES

Zachary Cohen
Non-Invasive Acute Neuromodulation and Measurement of Epileptogenicity

Rosie Coleman
Functional and structural plasticity after epilepsy surgery

Georgia Doumou
Mapping human brain development at new spatial resolutions using Artificial Intelligence and 7T Magnetic Resonance Imaging: Application on Paediatric Epilepsy

Maria Eriksson
Cognitive outcomes after neurosurgical treatment for focal epilepsy: developing a neuroanatomical predictive model for clinical decision making

Amy Fairchild
Characterisation of high-risk paediatric brain tumours and their aberrant gene networks

Xiyu Feng
Functional brain connectomics: implications for post-surgical outcomes in children with focal epilepsy

Robert Flynn
Timings and origin of Hypoxic Ischaemic Encephalopathy in the low-and middle-income countries

Anna Keegan (IfWH)
AAV9 medicated gene therapy for pyruvate dehydrogenase deficiency

Nandaki Keshavan
Gene Therapy for Deoxyguanosine Kinase Deficiency

Jane Kung
Epilepsy in infancy – relating phenotype to genotype

Mei-Ju Lai *Investigating cellular identity in childhood epilepsy*

Jade Lau
Zebrafish models of vitamin B6-dependent epilepsies

Jyoti Mangal
Developing Ultra-High Resolution Quantitative MRI at 7T for Clinical Applications

Rebecca Meagher
Optimising EEG hardware for use at 7T for effective deployment in simultaneous EEG-fMRI for better epilepsy surgery localisation

Martina Messina
Can one model Primary Mitochondrial Disorders and can this be used to identify biomarkers for diagnosis, follow up and therapeutic targets?

Jamie Norris
Variability in epileptiform activity and the brain response to stimulation

Jack O'Brien
Novel models of autoimmune epilepsies

Francois Okoroafor
Multi-modal network-guided paediatric epilepsy surgery Neuromodulation biomarkers in paediatric epilepsy, Network connectivity: MRC iCase

Rory Piper
Network-guided epilepsy surgery for children

Vaisakh Pulappatt Azhakapath
Timings and orgin of Hypoxic Ischaemic Encephalopathy i the low-and-middle income countries

Mathilde Ripart
Automated detection of MRI pathology in epilepsy

Oliver Sherwood
Steering epilepsy networks in real time: a multimodal approach

Izabella Smolicz
The biology of paediatric central nervous system tumours at post-mortem

Ulrich Stoof
Modelling synaptic constraints on interictal brian activity

Damjan Veljanoski
Multi-modal network-guided paediatric epilepsy surgery Neuromodulation biomarkers in paediatric epilepsy,

Network-guided paediatric epilepsy surgery: retrospective neuroimaging cohort study

Aitkaterini Vezyroglou
Deep phenotyping of alternating hemiplegia in childhood

Ella Whittle (SGUL)
Elucidating the genetic background of rare neurological diseases: with a focus on paediatric neurological disorders

Lottie Wood
Comprehensive Neuroimaging characterization of neurodegeneration and brain plasticity in children with Rasmussen Syndrome

Yutong Yao
Modelling epileptogenic networks in concurrent iEEG-fMRI

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Young
Epilepsy

Research Publications

Primary Research

1. Adler S, D'Arco F, Mankad K, Kyncl M, Arzimanoglou A, Marusic P. **Harmonization of MRI sequences across ERN EpiCARE centers (2025)**. *Epilepsia Open*. 10(2):587-592. doi: 10.1002/epi4.13115.

2. Auvin S, Arzimanoglou A, Falip M, Striano P, Cross JH. **Refining management strategies for Lennox-Gastaut syndrome: Updated algorithms and practical approaches (2025)**. *Epilepsia Open*. 10(1):85-106. doi: 10.1002/epi4.13075.

3. Avsenik J, Benedik MP, Rogač M, Biswas A, Sudhakar S, D'Arco F, Löbel U, Mankad K. **Divergent Presentation of GRIN2B Neurodevelopmental Disorder in Monozygotic Twins: Case Report with Unique Imaging Phenotypes (2025)**. *Neuropediatrics*. 56(4):269-273. doi: 10.1055/a-2509-0348.

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5. Beniczky S, Trinka E, Wirrell E, Abdulla F, Al Baradie R, Alonso Vanegas M, Auvin S, Singh MB, Blumenfeld H, Bogacz Fressola A, Caraballo R, Carreno M, Cendes F, Charway A, Cook M, Craiu D, Ezeala-Adikaibe B, Frauscher B, French J, Gule MV, Higurashi N, Ikeda A, Jansen FE, Jobst B, Kahane P, Kishk N, Khoo CS, Vinayan KP, Lagae L, Lim KS, Lizcano A, McGonigal A, Perez-Gosiengfiao KT, Ryvlin P, Specchio N, Sperling MR, Stefan H, Tatum W, Tripathi M, Yacubian EM, Wiebe S, Wilmshurst J, Zhou D, Cross JH. **Updated classification of epileptic seizures: Position paper of the International League Against Epilepsy (2025)**. *Epilepsia*. 66(6):1804-1823. doi: 10.1111/epi.18338.

6. Beniczky S, Trinka E, Wirrell E, Specchio N, Cendes F, Helen Cross J. **Updating the ILAE seizure classification (2025)**. *Epilepsia*. 66(6):1824-1826. doi: 10.1111/epi.18399.

7. Cadwgan J, Goodwin J, Babcock B, Brick M, Chin R, Easton A, Green B, Hannan S, Inward RPD, Kinsella S, King C, Kurian MA, Levine P, Mallick A, Parr J, Partridge CA, Amin S, Lumsden D, Cross JH, Lim MJ; UK Childhood Neurological Disorders PSP Group. **UK research priority setting for childhood neurological conditions (2024)**. *Dev Med Child Neurol*. 66(12):1590-1599. doi: 10.1111/dmcn.16021.

8. Chari A, Hernan AE, Mahoney JM, Thornton R, Tahir MZ, Tisdall MM, Scott RC. **Single unit-derived connectivity networks in tuberous sclerosis complex reveal propensity for network hypersynchrony driven by tuber-tuber interactions (2024)**. *Sci Rep*. 14(1):31654. doi: 10.1038/s41598-024-80634-5.

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12. Coughtrey AE, Bennett SD, Stanick C, Chorpita B, Dalrymple E, Fonagy P, Helen Cross J, Ford T, Heyman I, Moss-Morris R; MICE Study Team; Shafran R. **Training and supervision of physical health professionals to implement mental health care in paediatric epilepsy clinics (2024)**. *Epilepsy Behav*. 157:109905. doi: 10.1016/j.yebeh.2024.109905.

13. Currin CB, Burman RJ, Fedele T, Ramantani G, Rosch RE, Sprekeler H, Raimondo JV. **Network models incorporating chloride dynamics predict optimal strategies for terminating status epilepticus (2025)**. *Neurobiol Dis*. 212:106966. doi: 10.1016/j.nbd.2025.106966.

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15. Dasgupta D, Chari A, Khan M, Moeller F, Tahir Z, McEvoy AW, Miserocchi A, Duncan JS, Sparks RE, Tisdall M. **Refining computer-assisted SEEG planning with spatial priors - A novel comparison of implantation strategies across adult and paediatric centres (2025)**. *Neurophysiol Clin*. 55(1):103038. doi: 10.1016/j.neucli.2024.103038.

16. Dasgupta D, Elliott CA, O'Keeffe AG, Rodionov R, Li K, Vakharia VN, Mirza FA, Tahir MZ, Tisdall MM, Miserocchi A, McEvoy AW, Ourselin S, Sparks RE, Duncan JS. **Computer-assisted stereoelectroencephalography planning: center-specific priors enhance planning (2025)**. *Front Neurol*. 16:1514442. doi: 10.3389/fneur.2025.1514442.

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20. Dhaliwal JK, Ruiz-Perez M, Chari A, Piper RJ, Tisdall MM, Hart M. **Deep brain stimulation for epilepsy: A systematic review and meta-analysis of randomized and non-randomized studies of thalamic targeting (2025)**. *Epilepsy Res*. 216:107607. doi: 10.1016/j.eplepsyres.2025.107607.

21. Mankel FL, Papandreou A, Mankad K, Richardson H, Aylett SE. **Diagnositic pathway and management of first seizures in infants with Sturge-Weber syndrome (2025)**. *Dev Med Child Neurol*. 67(1):111-118. doi: 10.1111/dmcn.15983.

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24. Dubenko A, Morelli R, Cross JH, Hall J, Kharytonov V, Michaelis R, Wiebe S; ILAE Emergency Task Force for Ukraine. **Mental health and quality of life of individuals with epilepsy during the war in Ukraine (2024)**. *Epilepsia*. 65(9):2718-2727. doi: 10.1111/epi.18052.

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Epilepsy in childhood:
Carers
Uniting with
REsearchers
...join the conversation"

We Need You

to help us strengthen the voice of children and young people with epilepsy and their families in research.

Following the launch of the first network of young people with epilepsy and their parents, whose sole purpose is to consult on the development of research projects across our partnership, we are keen to continue to grow. If you would like your experiences to ensure epilepsy research is answering the right questions in the right way, please get in contact and sign up to the E-CURe network by scanning the QR code below.

Glossary

Animal models
A non-human species used in medical research because it can mimic aspects of a disease found in humans

Assays
An investigative procedure in laboratory medicine for measuring the presence, amount, or functional activity of a target entity

Biophysical
Methods used in physics to study biological phenomena

Calcium imaging
A technique to optically measure the calcium levels in a cell or tissue

Chronic
Long term

Co-morbidities
Medical conditions that are simultaneously present in a patient

Computational modelling
A mathematical model to study the behaviour of a complex system by computer simulation

Copy number variants
When the number of copies of a particular gene varies between individuals

Cortical
Relating to the outer layer of the uppermost part of the brain

Cox regression
A statistical test

Cryogenic
The production of, and behaviour of, materials at very low temperature

Dietetics
Branch of knowledge concerned with the diet and its effects on health

Electroencephalography (EEG)
A test that detects electrical activity in your brain using small electrodes attached to your scalp. Your brain cells communicate via electrical impulses and activity shows up as wavy lines on an EEG recording

Epidemiological
The branch of medicine which deals with the incidence, distribution, and control of diseases

Epilepsy-dyskinesia
Disorders characterised by recurrent episodes of abnormal movements, co-occurring with epilepsy or other episodic neurological symptoms

Epileptiform discharges
Seen on an EEG, meaning spikes, polyspikes, sharp waves, or spike and slow-wave complexes without observed clinical seizures

Epileptogenesis
The gradual process by which a normal brain develops epilepsy or, the area of epileptogenesis is the area of the brain which causes a patient's epilepsy

Functional validation (of disease-causing genes)
The process of determining whether a particular genetic mutation is causing a disease

Genomics
The study of whole genomes of organisms, and incorporates elements from genetics

Genotype
An organism's set of heritable genes that can be passed down from parents to offspring

Health economics
The study and understanding of how society allocates resources to healthcare and the resource needs of specific healthcare issues

Hemiparesis
Weakness of one entire side of the body

Immunofluorescence
A method in biology that relies on the use of antibodies chemically labelled with fluorescent dyes to visualise molecules under a light microscope

Intractable
Untreatable, hard to manage

Language lateralisation
The phenomenon in which one hemisphere (typically the left) shows greater involvement in language functions than the other

Lesion
A region in an organ or tissue that is abnormal from injury or disease

Magnetoencephalography (MEG)
Functional neuroimaging technique for mapping brain activity by recording magnetic fields produced by electrical currents occurring naturally in the brain

Memory lateralisation
The phenomenon in which one hemisphere (typically the left) shows greater involvement in memory functions than the other

Miss-sense mutation
A point mutation in a gene in which a single nucleotide change results in a codon that codes for a different amino acid

Multi-omic
Or *integrative omics*, is a biological analysis approach in which the data sets are multiple "omes", such as the genome, proteome, transcriptome, epigenome, metabolome, and microbiome

Myoclonia
A form of epileptic seizure manifesting with jerks of the muscles

Natural history
The progression of a disease process in an individual over time, in the absence of treatment

Optically pumped magnetometers (OPM)-MEG
A new type of MEG instrumentation, promising several advantages compared with conventional scanners: higher signal sensitivity, better spatial resolution, more uniform coverage, lifespan compliance, free movement of participants during scanning, and lower system complexity.

Pancytopenia
A condition that occurs when a person has low counts for all three types of blood cells: red blood cells, white blood cells, and platelets

Pathophysiological mechanisms
The cause of a disease associated injury

Phenotype
An individual's observable traits, such as height, eye colour, and blood type. The genetic contribution to the phenotype is called the genotype

PPI
Patient and public involvement

Practice paper
Evaluative summaries of scientific and evidence-based information that address practice topics. Practice papers are often done in emerging areas that might not have sound scientific data yet

Putative variants
A segment of DNA that is believed to be a gene. Putative genes can share sequence similarities to already characterised genes and thus can be inferred to share a similar function, yet the exact function of putative genes remains unknown

Sanger sequencing
A method for determining the nucleotide sequence of DNA

Status epilepticus
A single seizure lasting more than five minutes or two or more seizures within a five-minute period without the person returning to normal between them

Structural correlates
Structural anomalies which correlate to symptoms

Targeted treatment
Treatments which target specific symptoms and potential causes of disease. These treatments are disease modifying

Therapeutic radiofrequency thermocoagulation
A technique of controlled thermal ablation of tissues

Trio whole genome sequencing (WGS)
Whole exome sequencing is a comprehensive method for analysing entire genomes. Trio whole exome sequencing refers to the sequencing of the entire genome of a patient and their biological parents

Western blotting
A widely used analytical technique in molecular biology and immunogenetics to detect specific proteins in a sample of tissue extract

Young Epilepsy

We are the children and young people's epilepsy charity

We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

together we create possible.

For more information on our research, or to get involved please contact:

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